



## DEPARTMENT OF HEALTH AND HUMAN SERVICES

### Centers for Disease Control and Prevention

[30Day-22-22IK]

#### Agency Forms Undergoing Paperwork Reduction Act Review

In accordance with the Paperwork Reduction Act of 1995, the Centers for Disease Control and Prevention (CDC) has submitted the information collection request titled Study to Explore Early Development (SEED) Follow-up Study to the Office of Management and Budget (OMB) for review and approval. CDC previously published a "Proposed Data Collection Submitted for Public Comment and Recommendations" notice on October 4, 2021 to obtain comments from the public and affected agencies. CDC did not receive comments related to the previous notice. This notice serves to allow an additional 30 days for public and affected agency comments.

CDC will accept all comments for this proposed information collection project. The Office of Management and Budget is particularly interested in comments that:

- (a) Evaluate whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information will have practical utility;
- (b) Evaluate the accuracy of the agencies estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used;

- (c) Enhance the quality, utility, and clarity of the information to be collected;
- (d) Minimize the burden of the collection of information on those who are to respond, including, through the use of appropriate automated, electronic, mechanical, or other technological collection techniques or other forms of information technology, e.g., permitting electronic submission of responses; and
- (e) Assess information collection costs.

To request additional information on the proposed project or to obtain a copy of the information collection plan and instruments, call (404) 639-7570. Comments and recommendations for the proposed information collection should be sent within 30 days of publication of this notice to [www.reginfo.gov/public/do/PRAMain](http://www.reginfo.gov/public/do/PRAMain). Find this particular information collection by selecting "Currently under 30-day Review - Open for Public Comments" or by using the search function. Direct written comments and/or suggestions regarding the items contained in this notice to the Attention: CDC Desk Officer, Office of Management and Budget, 725 17th Street, NW, Washington, DC 20503 or by fax to (202) 395-5806. Provide written comments within 30 days of notice publication.

Proposed Project

Study to Explore Early Development (SEED), Follow-up Study - New  
- National Center on Birth Defects and Developmental  
Disabilities (NCBDDD), Centers for Disease Control and  
Prevention (CDC).

### Background and Brief Description

In 2016, an estimated one in 54 children eight years of age living in 11 communities across the United States had autism spectrum disorder (ASD), a developmental disability that can cause significant social, communication, and behavior challenges. Total annual costs associated with ASD have been estimated between \$11.5-60.9 billion (2011, US dollars), yet major gaps in knowledge remain about risk factors for ASD, and associated challenges and needs for persons with ASD and their families. Additionally, while most research on ASD has focused on children, ASD is considered a lifelong condition, and although an estimated 70,000 to 111,000 youth with ASD turn 18 years of age annually, little is known about the transition to adolescence and adulthood for persons with ASD. Despite the call to address transition and lifespan issues in the Autism CARES Acts of 2014 and 2019, only 2% of ASD funding from 2008-2018 was spent on lifespan issues. The 2016-2017 Interagency Autism Coordinating Committee (IACC) Strategic Plan highlighted the need for more information about the services and support needed to maximize the quality of life for people on the autism

spectrum, especially as individuals with ASD progress into adulthood.

The Study to Explore Early Development (SEED) was originally initiated to address the Children's Health Act of 2000, which mandated CDC to conduct ASD surveillance and implement research programs to address the number, incidence, and causes of ASD and related developmental disabilities. SEED was a multi-phase, multi-site, case-control study comparing children with ASD, identified at ages 2-5 years, to children with other non-ASD developmental disabilities (DD), and from the general population (POP). SEED was initially implemented in three phases during 2007-2021. The current information collection request is to conduct longitudinal follow-up studies of SEED 1-3 participants at older ages, thereby addressing the priorities established in the Autism CARES Acts of 2014 and 2019, and the need for research highlighted in the IACC Strategic Plan.

Given the size of the original SEED birth cohorts and the wealth of baseline information collected, a follow-up study of participants can help us address the research gaps described above. The information collected from this study will allow us to better understand the developmental trajectory of children with ASD, their health outcomes and co-occurring conditions at older ages, and the associated early predictors of these outcomes, including intellectual abilities.

The data collected in this study also provides the opportunity to obtain important self-reported measures of well-being among young adults with ASD. Recent evidence suggests that individuals with ASD, with average to above average levels of intellectual functioning, may still struggle with activities of daily living. Yet, adults with special needs are often required to have an intellectual disability in order to qualify for services. This data will allow investigators to describe the gap between intellectual ability and daily living skills in adolescents with ASD to inform public policies on eligibility for services. Additionally, because most SEED 1 participants will reach young adulthood (i.e., age 18 years) in years 2021-2026, data collected through this study will provide an opportunity to assess changes in service access and utilization that may occur following high school exit. This period is particularly challenging for young adults with ASD who can experience poor outcomes across multiple domains (i.e., employment, education, social engagement, independent living, and access to health and mental health care service, in association with the loss of well-integrated school-based services). Hence, through surveying SEED 1 participants before and after their anticipated exit from high school, data collected through this study could provide important information on the loss of services and emerging issues that can inform service delivery and programs on the supports needed to achieve greater independence.

Initial follow-up surveys of SEED participants will be conducted with the parents of the children who previously participated in SEED because it is the parents who provided consent for follow-up studies. However, many emerging issues surrounding the transition to adulthood among adolescents with ASD require self rather than parental report (e.g., self-reported symptoms of anxiety, depression, quality of life, social camouflaging, gender identity, sexuality, and relationships). Therefore, children who originally participated at age 2-5 years who are now adolescents and young adults, will be contacted through their parents and asked if they wish to provide informed consent for participation in surveys.

CDC requests OMB approval for an estimated 2,089 annual burden hours. There are no costs to respondents other than their time to participate.

#### Estimated Annualized Burden Hours

Type of Respondents	Form Name	Number of Respondents	Number of Responses per Respondent	Average Burden per Response (in hours)
Caregiver	Review of enrollment call script and consent for first follow-up survey	2,057	1	10/60
Caregiver	First follow-up core survey of SEED 1-3 caregivers	1,234	1	40/60
Caregiver	First follow-up survey supplement for	411	1	20/60

	caregivers of children			
Caregiver	First follow-up survey supplement for caregivers of adolescents	411	1	20/60
Caregiver	First follow-up survey supplement for caregivers of young adults	411	1	20/60
Caregiver	Review of enrollment call script and consent, and Second follow-up survey of SEED 1 caregivers	350	1	10/60
Caregiver and Adult Child	Review of enrollment call script and consent by caregivers and young adults	165	1	10/60
Adult Child	Second follow-up survey of SEED 1 adult children	165	1	30/60
Children aged 8-22 years and their caregivers	Review of enrollment and informed consent or assent, In-person assessment of intellectual abilities	229	1	90/60

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